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AUTHOR Kappel, Bruce
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ABSTRACT

The first of five volumes on the means by which Canadian communities can reduce the incidence of mental retardation, minimize existing impairment, and improve the quality of life of the mentally retarded, this booklet provides an overview of the types of conditions leading to mental handicap and what can be done to prevent or ameliorate those conditions. The approach is based on a four-level prevention model which distinguishes between impairment, disability, handicap, and the feedback role of the environment. After an introduction, there are sections dealing with the following specific topics and examples: known causes of mental handicap (fetal alcohol syndrome, child abuse); causes of handicapping circumstances (failure to diagnose mental handicap); the reality versus the label (a case study); recommendations for change (better antenatal and perinatal health records, frequent home visits to newborns); universal barriers to change (service delivery discontinuities); gaps and problems in Canada's existing system (need for better genetic counseling); causes for optimism--opportunities in Canada (better public understanding of mental handicaps); individual responsibility; and proof that changes can be made (the phenylketonuria story). (DB)

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MAKING A DIFFERENCE:

What communities can do to prevent mental handicap and promote lives of quality

Volume I: Planning for change

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MAKING A DIFFERENCE
Planning for change

Writer: Bruce Kappel

Series editor: Miria Ioannou

Prevention Project Resource Team
CHAIRPERSON
Robert Haslam, M.D., F.R.C.P. (C)
PROJECT COORDINATOR
Diane Richler
Graham Chance, F.R.C.P. (C)
Alan Etmanski
Marie Gallagher
Bernard Graney, Ph.D.
Ian MacLean
Martha Piper, Ph.D.
Kathryn Sullivan
Yves Talbot, M.D., F.R.C.P. (C)
Louise Vinet Lanteigne
Joseph Waters, Ed.D.
Colleen Wieck, Ph.D.

Designer: Barbara Bailey

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Kinsmen Bldg., York University Campus
4700 Keele St.
Downsview, Ontario M3J 1P3
CANADA

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What communities can do to prevent mental handicap and promote lives of quality

Volume I: Planning for change

National Institute on Mental Retardation

NOTE

The examples and stories in **Making a Difference** are about real people and real situations. In some cases the names of individuals have been changed to avoid unwanted attention to families and children. We do encourage you, however, to contact us at NIMR if you would like to receive more information on a specific example or story.

Dedication

Making a Difference is dedicated to Dr. Ronald J. Christie who spearheaded the involvement of the National Institute on Mental Retardation in the field of prevention. His death, in 1985, was a blow to the movement for persons with mental handicaps. Among his other accomplishments, Dr. Christie had also been an NIMR Associate, a former Vice-President of the Canadian Association for Community Living, a past President of the Metropolitan Toronto Association for the Mentally Retarded and a member of the American Association on Mental Deficiency.

Dr. Christie was a general practitioner in London, Ontario and a member of the Faculty of Medicine at the University of Western Ontario.

We believe that **Making a Difference** is a manifestation of Dr. Christie's hope that NIMR would take a leading role in not only helping to prevent mental handicaps, but also in promoting lives of quality for persons with mental handicaps.

Photographs

The photographs in Making a Difference are meant to illustrate certain situations and do not necessarily represent specific individuals or events. Photographs of specific persons, however, are acknowledged.

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PREFACE

In May, 1983, the Canadian Association for Community Living (formerly the Canadian Association for the Mentally Retarded) convened a group of approximately twenty people from across Canada in order to review developments in the field of prevention, to discuss the role of CACL and its member provincial and local associations in the field of prevention, to gain a better understanding of the role of the federal government in the field of prevention, and to develop a feasible action plan for future CACL involvement in this area. This symposium, made possible largely through a grant from the Health Promotion Directorate of Health and Welfare Canada, was the culmination of several years' work on the part of CACL. Since 1976, CACL had had a committee responsible for the area of prevention, and in 1979, when the CACL's Board of Directors conducted a major self-evaluation of the association's goals and structure, prevention was identified as one of the major directions to be undertaken by CACL.

The national symposium concluded an extensive two-and-a-half year consultation process with all regions of Canada through which a nationwide consensus had developed regarding the need for CACL to serve as a national coordinator and clearing house for information as well as a lobbyist at the federal level and provider of technical support. CACL would be supported in this role by its National Institute on Mental Retardation.

A significant contribution to the conceptualization of the problem was made at the symposium by Ron Draper of Health and Welfare Canada. Mr. Draper outlined a prevention strategy model developed by the World Health Organization (WHO) which he applied and adapted in his Directorate. Indeed, it was the presentation of this model which enabled the symposium to integrate CACL's interest in prevention within the context of the organization's overall concerns.

The WHO model suggests that prevention strategies can be implemented at four levels: the level of impairment, the level of disability, the level of handicap and the level of feedback.

Impairment refers to a physiological or psychological loss or abnormality which would impair physical or mental function. Disability is a consequence of an impairment or a circumstance which prevents individuals from performing their social roles. Handicap refers to a disadvantage resulting from an impairment or disability that limits or prevents the fulfillment of social roles. The concept of feedback refers to situations where further impairments and disabilities are acquired as a result of handicapping circumstances.

This approach fit in very well with CACL's concerns which focus primarily on individuals living with a mental handicap. Consequently, the notion of working not only to prevent impairment from occurring but also to minimize existing impairment and promote lives of quality for individuals provided the impetus for **Making a Difference.**

Although in **Making a Difference** we do not use the WHO terminology in such a specific way as described above, the WHO model provides the framework for these publications.

Making a Difference is a series of five monographs which address how communities can reduce the incidence of impairments which cause mental retardation and also how they can reduce those disabilities and handicaps which are environmentally caused - often by where people live or work or go to school.

A heartfelt thank you is extended to the Prevention Project Resource Team who developed the framework and content of this series, and to the staff of the National Institute on Mental Retardation for producing the final documents.

Sincere appreciation is offered to Dr. Maureen Law, Associate Deputy Minister, Health and Welfare Canada and to Mr. Ron Draper, Director General, Health Promotion Directorate, Health and Welfare Canada, for their support and direction in the process which we hope will "make a difference" for thousands of Canadians.

Robert H.A. Haslam, M.D., F.R.C.P. (C)
Chairperson
Prevention Committee, CACL
and
Prevention Project Research Team, NIMR

INTRODUCTION

Making a Difference: what communities can do to prevent mental handicap and promote lives of quality is a series of publications dealing with a topic that, in many ways, touches the majority of Canadians.

Most people know or know of someone with a mental handicap. Many of us have children or are planning to become parents. Some of us are professionals working to better people's lives. Preventing mental handicaps from occurring or from becoming more significant is an issue that affects a great number of us quite directly.

In this decade, between 200,000 to 600,000 Canadians will either be diagnosed as having a mental handicap or will need services because of a mental handicap. Assuming that all of these individuals are connected to a family, at least an additional 400,000 to 1,200,000 Canadians will be involved as parents. If we include brothers and sisters, the extended family, friends, neighbours and professionals, the number grows to major proportions.

So, what do we mean by preventing mental handicaps and their impact, in relation to these vast numbers of individuals who are affected directly or indirectly?

Traditionally, prevention has been looked at from three perspectives:

- preventing a handicapping condition from occurring (primary prevention);
- correcting an existing condition (secondary prevention); and
- lessening the impact of a condition (tertiary prevention).

This approach to prevention focuses on conditions and individuals, mostly in medical or physical terms. Changing views, however, have added new dimensions to the notion of prevention.

We now realize that when a person is born with or acquires a mental handicap, that is not the most important thing about that person. Rather, we can look at the abilities and potential of the individual and respond to those qualities.

Another realization is that a person's ability to perform a number of social roles is perceived as essential. For example, one has to: orient oneself to one's surroundings; be physically independent; be effectively mobile; have an occupation; and participate and maintain social relationships. There are many arrangements that can be made to ensure that an individual can perform these roles to the fullest extent possible despite a handicap.

We have also come to see that the individual's ability to perform these social roles can depend as much if not more on the way the world works than on how the person's body works. Social and physical environments can also handicap people by not providing appropriate support and adaptations.

Furthermore, additional health or emotional problems can result from conditions and circumstances that handicap people.

In the context of these changing views and new insights, then, the concept of prevention takes on a much richer meaning that looks at the whole person, the person's abilities and disabilities and the barriers and opportunities that are present in our communities.

So, when we discuss the prevention of mental handicaps and their impact, we mean:

- preventing the occurrence or impact of conditions that cause mental handicap;
- preventing circumstances, actions and practices that cause people with mental handicaps to become socially disadvantaged, isolated and unable to perform social roles;
- preventing conditions, circumstances and practices that cause people with mental handicaps to acquire further handicaps and become even more dependent.

Any prevention approach, however, must be complemented with the promotion of lives of quality. Prevention and promotion are both related to the potential of individuals and the potential of society to support individuals so they can live lives of quality.

In this sense, promotion of lives of quality means:

- promoting the strengths of individuals;
- promoting the access of individuals to supports and opportunities which will enable them to perform social roles more competently;
- promoting the adaptation of the social and physical environment;
- promoting the view that persons with handicaps are whole people with rights and responsibilities.

The goal of **Making a Difference**, then, is to assist and encourage action by individuals, groups and governments to ensure that, whenever possible, citizens of Canada do not acquire mental handicaps and that when they do, they are supported to develop to their potential.

There are many things that we can do to prevent mental handicaps. There are also many things we can do to make sure that those affected can develop their abilities. But to make a positive difference, we must not only know what works well but also make sure that it is actually done. Good ideas need to be implemented, not just discussed.

Before this can happen, however, we need to identify what the priorities should be; that is, the key actions which will be most effective in preventing handicaps and eliminating handicapping circumstances.

We hope that **Making a Difference** will challenge, promote and incite effective actions based on pertinent knowledge. We also hope to help individuals, groups and government to understand their own roles and act *collectively* to ensure lives of quality for persons with handicaps.

More specifically, the series will be of interest to any individual or member of a group who can affect change. For example:

- groups of parents who have gathered in associations and action groups;
- groups of people with mental handicaps who have come together in their desire to contribute to society;
- decision-makers at all levels of parent associations;
- decision-makers in many Canadian organizations which address common issues such as the health, education, employment, and human and civil rights of Canadians;
- professionals who want to make a positive difference in people's lives, have services available to all people and contribute to the dignity and quality of life of the people they serve and support;
- any policy-maker or public servant who wants to foster a society which respects the rights of all citizens, encourages their participation and contribution to the common good, and supports and protects those who are vulnerable;
- all Canadians who are planning to have children, because any child can be born with or later develop a mental handicap.

The first volume of the series, **Planning for change,** is an overview of what we can prevent and promote and ways in which we can create a foundation for action. It looks at current obstacles and suggests ways of overcoming them.

Subsequent volumes focus on **The well-being of babies and young children** and on **Helping children live, learn and grow in their communities.** Prevention and promotion issues pertinent to adults with handicaps will be looked at in two future publications.

WHAT CAUSES MENTAL HANDICAP?

It is estimated that the causes of 50 per cent of all cases of mental handicap are unknown. However, there are many known causes. Generally, these causes are classified in terms of when they have their effect or when they occur. Genetic and prenatal causes emerge before conception or after conception while the baby is developing in the mother's womb. Perinatal causes have their effect at or during birth. Postnatal causes occur after birth during the early years of a child's development.

Known causes of mental handicap

Genetic/prenatal

At conception or during pregnancy:
- chromosomal abnormalities (Down syndrome, Trisomy 18);
- inborn errors of metabolism or hormonal deficiencies such as Phenylketonuria (PKU), Hurler's syndrome, Tay-Sachs disease and congenital hypothyroidism;
- other hereditary syndromes such as X-linked hydrocephalus;
- neural tube defects such as spina bifida;
- infections such as rubella and toxoplasmosis;
- toxins including alcohol, drugs and mercury.

Perinatal

At birth:
- asphyxia causing an interruption of the flow of oxygen to the brain (e.g., umbilical cord cutting off blood supply);
- cerebral damage or injury during the birthing process;
- prematurity associated with insufficient brain development at birth;
- infections such as meningitis or encephalitis.

Postnatal

Early years of development:
- brain injury from such incidents as abuse or motor vehicle accidents;
- brain damage from choking or seizures;
- infections such as meningitis or encephalitis;
- poisoning from lead, mercury or carbon monoxide;
- hormonal or metabolic problems such as hypothyroidism and hypoglycemia;
- lack of stimulation or emotional deprivation.

Recognizable and frequent causes

The most frequent:
- Down syndrome;
- neural tube defects;
- fetal alcohol syndrome;
- complications of prematurity;
- difficult births;
- perinatal asphyxia (lack of oxygen);
- social and environmental factors (maternal infection, accidents, poisons, toxins, abuse and neglect).

Risk factors

Increasing the likelihood that a child may be born with a handicap:
- maternal smoking;
- poor maternal nutrition;
- maternal history of pregnancy complications or abortions;
- maternal age (very young or older);
- poverty;
- pregnant women working with toxic substances, radiation or organic solvents;
- future fathers working in toxic environments.

Eliminated causes

Almost totally eliminated due to advances in diagnosis, treatment and preventive medicine:
- PKU;
- Tay-Sachs disease;
- infections such as congenital rubella and measles and encephalitis;
- kernicterus related to bilirubin and Rh factor (Rh incompatibility).

Causes of handicapping circumstances

As our understanding of the initial causes of mental handicap increases, so does our knowledge of handicapping circumstances. These circumstances are generally of three types:

- conditions and practices which prevent individuals from developing their skills;
- conditions and practices which prevent individuals from performing important social roles;
- conditions and practices which cause additional health or emotional problems.

Such circumstances can result from active or passive practices. Although they are often not a result of bad intentions they are frequently a result of inappropriate knowledge, no action or ineffective action. The following actions are likely to result in handicapping circumstances:

Failure to diagnose:

- failing to diagnose or identify mental handicap or providing improper treatment when diagnostic methods are known.

Failure to treat:

- withholding adequate immunization policies and procedures;
- denying lifesaving or corrective surgery for people with neural tube defects or Down syndrome;
- failing to refer families for genetic counselling.

Failure to serve:

- exposing individuals to non-stimulating and non-therapeutic environments and denying them access to any physiotherapy, speech therapy and behavioural management services that they may need;
- denying them access to positive environments, often through lack of access for wheelchairs, attendant care or accessible transportation;
- overmedication or inappropriate medications which cause additional problems.

Failure to develop abilities:

- teaching individuals to develop skills and abilities which are not functional in their lives, at the expense of learning useful skills (i.e., skills related to obtaining and retaining work).

Discrimination:

- denial of employment, housing and social opportunities because of prejudice, segregation or congregation, either overtly or subtlely (i.e., workers informally voting on whether or not a handicapped co-worker should be invited to an office party).

MENTAL HANDICAP: THE REALITY VERSUS THE LABEL

Persons with mental handicaps have limited intellectual capacity, which often results in a limited ability to adapt to social situations. From an early age they have trouble learning and conceptualizing, and may experience difficulties in communication, coordination and dexterity, or in social skills and behaviour.

Individuals with needs in these areas have usually been labelled as "mentally retarded" and have been grouped together and categorized. Over the years, laws and procedures have been developed that define how various "categories" of people are treated medically and socially. Being labelled has entitled some people to the benefits of services while isolating and segregating others. If someone was considered "too handicapped" to benefit from a specific service, he or she might simply have been excluded and not given any service at all.

Labelling also has the effect of grouping together individuals of varying abilities and implying that they have much more in common than is actually the case.

It is also important to note that some who would be labelled in one community may not be labelled in another community, depending on the social expectations about "normal" intelligence. That is not to say that mental handicap is only relative but that our idea of mental handicap should not be a barrier to individuals. Definitions do help identify those who require assistance but very often that assistance is very similar to the kind of support we all need to function in society.

One of the most detrimental aspects of labelling is that it frequently sets limits on what an individual can achieve. It is often used not so much to define abilities but rather to determine a person's future.

In terms of prevention then, labelling can have devastating effects on how an individual is perceived and what kind of support he or she receives to enhance abilities and prevent the acquisition of further handicap.

A case in point: Justin Clark

At two years of age, Justin Clark was diagnosed as having cerebral palsy, hydrocephalus and a mental handicap, possibly due to a lack of oxygen to his brain at birth.

At three years of age, Justin, who was institutionalized, was described as having a mental age of six months and "a potential intellectual level prognosis of a possible mid-imbecile level."

Later in life, he was described as "moderately mentally retarded and due to his severe physical handicaps, he will need permanent medical and nursing care such as is available in (the institution)."

At thirteen, professionals with insight and vision looked beyond his classification and saw "a very bright and receptive boy" with "many questions which had obviously been stored up for many years." They assisted him to communicate and, as a result, "his progress in terms of cognitive development, his development in terms of perceptions of things, was really quite amazing."

At twenty years of age, Justin Clark, wanting to be recognized as a citizen and be able to live in the community in a group-living situation with friends, went to court and proved his mental competence to the judge, who said:

> *Justin is able to communicate effectively...he has the great gift of friendship and extraordinary gifts of sincerity, trust and co-operation...he has a passion for freedom as well as a love of family...he has a unique part to play in our compassionate, interdependent society...*
>
> *I find and I declare Matthew Justin Clark to be mentally competent.*

As a result of the trial, and the views of many people involved in his life, Justin Clark moved swiftly from being seen as someone at a "possible mid-imbecile level" to a citizen. He moved from the institution to the community.

For Justin Clark, whatever initial limitations of intellectual capacity he experienced early in life were thought to have occurred because he required resuscitation at birth. It is not known whether that cause could have been prevented in his case. It also appears clear that a great deal of his subsequent and apparent mental handicap was linked to the expectations that others had of him, the expectations defined in part by his classification.

Justin Clark's experience is not unlike that of many other Canadians. For him and them, we must:

- *prevent initial limitations in intellectual functioning;*
- *prevent low expectations from limiting a person's development;*
- *promote the development of abilities;*
- *promote optimism and high expectations.*

BUILDING THE FUTURE

In school, we learned about different scientific breakthroughs and inventions – electricity, the telephone, smallpox immunization, insulin, and so on. These breakthroughs were often presented as the simple struggles of committed scientists, whose discoveries caused the world to change quickly and radically.

In fact, breakthroughs in knowledge do not always result in new ways of acting. When new knowledge conflicts with prevailing values, economic and social interests, financial situations and other realities, traditional ideas often prevail.

In Canada and the United States, there have been numerous individuals, task forces, committees, commissions, organizations and policy makers who have made discoveries, recommended a wide array of actions and developed systematic approaches – all related to prevention and promotion. Much has happened as a result of such discoveries and recommendations. Much remains to be done.

Recommendations for change

Among the many reports and writings in the field, the following were reviewed in order to identify some of the ideas which have been consistently recommended:

- The Canadian Organizing Committee, International Year of Disabled Persons (1982);
- The Report of the Special Committee on the Disabled and the Handicapped (The Obstacles Report) (1981);
- The Canadian Institute on Child Health Information Papers on the Prevention of Handicap (1981);
- The Federal Task Force on High Risk Pregnancies and Prenatal Record Systems (1982);
- The Report of the Advisory Committee on Reproductive Medical Care to the Minister of Health for Ontario (1979);
- Canadian Association for the Mentally Retarded Regional Symposia on Prevention (1982);
- The United Nations' World Program of Action Concerning Disabled Persons (1983);
- The (United States) President's Committee on Mental Retardation (1980);
- The Maine Planning and Advisory Council on Developmental Disabilities (1983);
- The 6th Plan of France (as described by Wynn and Wynn, 1976);
- Published papers by Crocker, Milunsky, Haslam, Stark, McCormack, Meier, Dunn, and Rosenbaum.

Some of the common themes and recommendations from these organizations and individuals are as follows:

Systems and policies:
- systematic and coordinated activity with focal points for responsibility;
- active information dissemination related to clear policies and strategies adopted by various levels of government.

Research:
- expanded research and systems of surveillance related to cause, incidence and prevalence, specific conditions, hazards and specific techniques of intervention;
- wide and active dissemination of the findings of this research.

Health care:
- expanded, improved, accessible and high-quality primary health care, pre- and perinatal care systems, maternal and child health care;
- more effective antenatal and perinatal health records;
- specific attention to neonatal resuscitation and intensive care; low birth weight; premature and difficult births; teen pregnancies; poor populations; nutrition; and newborn screening;
- incentives for medical practitioners to encourage them to engage in prevention practices and refer patients to other services.

Early intervention and follow-up:
- family life and parenting education;
- frequent and regular home visits to newborns and their families;
- regular health care monitoring and screening;
- improved access to in-home and centre-based developmental programs;
- a system of parent training linked to pre-school and school programs.

Family planning and counselling:
- genetic screening and referrals for counselling;

- family planning, especially for very young and older women;
- good information on the choices available.

Smoking, alcohol and drugs:
- measures to restrict these substances during pregnancy.

Immunization/isoimmunization:
- aggressive vaccination programs for children and working mothers;
- compulsory immunization;
- screening of immunization levels in the population;
- compulsory screening re Rh compatibility among pregnant women.

Accidents/safety hazards:
- regulations, training, adaptations, standards, penalties and monitoring of work environments and contact with hazardous materials;
- identification and eradication of toxic substances;
- active screening for lead poisoning;
- compulsory seat belt and child carrier legislation.

Parent and public education:
- education for parenthood and planned pregnancies;
- education and public health activities related to lifestyle, early recognition, adequate health care, dangers, causes and available support services;
- helpful tools and incentives to assist and encourage parents to seek appropriate health care and monitor their child's progress.

Professional education:
- dissemination of research and evaluation information;
- preparation for specific practices and systems;
- education about the need to refer patients to other services.

Many of these ideas and recommendations are being put into practice but rarely systematically or universally. The issue at hand is not to develop new recommendations but rather to ensure the effectiveness and accessibility of those ideas already developed.

There are also a number of issues and dangers to consider when implementing such ideas.

Issue: people who have factual knowledge about what works often have little knowledge about how to get good ideas implemented.
Danger: good ideas may not get implemented.

Issue: people who do know how to get ideas put into practice are not always well informed about which actions will be the most effective.
Danger: ineffective ideas may get implemented.

Issue: people who have commendable ideas and know how to put them into practice in their own communities are not always known to other people in other communities.
Danger: beneficial ideas only get put into practice in a few places.

Issue: people who want to accomplish something often look to see what is *happening,* rather than what is *working* in other communities. They then adopt those methods without being critical of them.
Danger: inappropriate ideas get put into practice in many places.

Issue: ideas and actions are not continually evaluated in light of new knowledge or results.
Danger: good ideas are implemented, but are not improved upon or replaced by better ideas.

Furthermore, there are often barriers to change.

Universal barriers to change

The following barriers to change have been identified by several leading experts (Boggs; Maine; U.S. General Accounting Office) and are relevant to the lives and futures of persons with a mental handicap:

- There are disfunctions and discontinuities in services provided for those who are mentally handicapped, as well as the professional organizations responsible for those services.
- There is often a lack of communication and collaboration among voluntary organizations and between voluntary and professional groups.
- There is a lack of political sophistication of groups seeking social change and implementing recommendations for prevention.
- The success of prevention strategies is usually gauged by a reduction of mortality rates, rather than prevention of handicap.
- Present funding does not permit agencies to deliver programs. This restricts public access to already over-crowded, existing programs. Nor does current funding permit agencies to develop or implement new programs.
- Funding is often available only for time-limited, rather than ongoing, projects.
- Physicians are not reimbursed for prevention-related services, which renders those services inaccessible to people who cannot afford them.

- Public education programs are only directed to specific client groups or limited target areas within the general public.
- At the government level, there is a lack of coordination regarding who is responsible for activities, resulting in unnecessary duplication of services. As well, prevention-related activities often suffer from low visibility due to lack of information exchange.
- There is insufficient analysis of needs and programs in prenatal care. This has led to inadequate analysis of the medical consequences of low birth weight and premature birth.
- Lead poisoning is not fully recognized as a problem and, therefore, screening is not routinely done.

Gaps and problems in Canada's existing system

The Canadian Association for Community Living, with assistance from Health and Welfare Canada, sponsored four regional symposia on prevention across Canada in 1981.* There, the experts identified a number of gaps and problems in our existing system, which serve as barriers to action by professionals, parents and organizations:

- Prevention of handicap was not rewarded in a fee-for-service system of reimbursement of physician costs.
- Primary physicians were reluctant to refer a mother with a high risk pregnancy to specialized facilities, fearing the loss of the patient, loss of fees and the "ripple effect" on other clients.
- Insufficient funds were available for the transporting of at-risk fetuses *in utero* to specialized facilities.
- Rubella immunization was not universal, nor mandatory for school children and all women after delivery in hospital.
- There were tremendous gaps in the availability of genetic counselling.
- The Canadian government and the public had not placed a high priority on the needs and rights of children, including the right to be born healthy.
- All professionals were not trained, which would give them a full and adequate understanding of both prevention and promotion.

*Report of symposia available from NIMR on request.

- Many interventions (i.e., seat belts, immunization, public health visits to newborns) were not mandatory.
- There was non-compliance with recommended practices by professionals (i.e., not making referrals for appropriate specialized health care).
- Individuals resisted modifying their lifestyles (i.e., ignoring advice to stop smoking or not following prescribed diets).
- There was a lack of systems of quality assurance, monitoring and evaluation of programs.
- Individuals postponed or did not make contact for prenatal and post-natal care.
- There was a failure to duplicate successful programs.
- There was a lack of legislated human and civil rights.
- Action was restricted (including many of the above) because of lack of funding, accessibility to services, and so on.
- Raising the standard of living and health care among poor, disadvantaged and isolated groups seemed to be a problem of almost too large a scope.

Causes for optimism: opportunities in Canada

There are causes for concern, as illustrated in the preceding gaps and problems identified in 1981.

Nevertheless, there are also indications that more and more opportunities are available in support of purposeful action related to promotion and prevention. Some recent developments provide a more positive context for moving into the future:

- a growing understanding of the real abilities and skills of people with mental handicaps, including those with severe and multiple handicaps;
- heightened expectations among parents, professionals, ordinary citizens and policy makers about the rights of handicapped people and the quality of life they should enjoy;
- growing experience with the benefits of early, intensive and comprehensive support to individuals and families;

- recommendations from diverse organizations on varied topics, all of which relate to prevention and promotion;
- increased concern that public and private funds be used to purchase services that actually deliver what they are paid to deliver;
- increased awareness of the debilitating effects of uncoordinated, unsystematic services on individuals, families and communities;
- increased attention to the full array of policies, practices and circumstances related to prevention and promotion;
- a growing recognition of the fact that people with disabilities such as mental retardation, actually have *more in common* with their fellow citizens than they have differences;
- more and more people are remaining with their families and in their communities, returning to their communities from institutions and reinforcing our awareness that people with mental handicaps are indeed *members* of families, our communities and our society.

Each of us has an individual responsibility . . .

As potential parents, professionals and policy makers, as well as society as a whole, we can take

action to remove many of the barriers and to further the quality of life of community members with mental handicaps.

As individuals, we must:

- seek reliable advice and services from professionals and various organizations;
- remain informed so that personal and professional practices can be altered according to new findings and information;
- modify our lifestyles, particularly pregnant women and new families;
- not engage in harmful practices and refuse to be exposed to harmful environments and situations.

Admittedly, there are situations that make it difficult to act responsibly. Those situations might involve:

- a lack of sufficient knowledge;
- a lack of access to professional advice and services due to physical or financial limitations;
- conflicting life priorities.

While individual responsibility is a major issue in prevention and promotion, there are often broader social issues and actions that either assist or restrain people in making informed choices, gaining access to available opportunities and acting responsibly.

For that reason, societal issues are by far the most important issues when individuals do not act responsibly, because:

- up-to-date information is not available at the right time, in the right place, from the right person;
- services are non-existent or inaccessible because of cost, distance, prejudice, the requirement that families be separated, etc.;
- harmful conditions exist but are unknown to or beyond the control of the individual (for instance, toxic waste leakage, lead emission levels, hazardous work, and so on).

Proof that changes can be made: the PKU story

It is not always the case that recommendations and good ideas are not implemented on a large scale. The following example illustrates how individuals and groups discovered a good idea and then put it into practice.

Phenylketonuria, or PKU, is a metabolic disorder which, left untreated, causes mental handicap. An error in the processing of an essential amino acid (present in virtually all natural foods) leads to increased levels of phenylpyruvic acid in the blood, which inhibits brain growth and causes mental handicap and permanent damage to brain cells.

At present, there is no cure for PKU, but if it is discovered early, infants can be prescribed a special diet which will prevent brain damage and control the disturbing behaviour which often accompanies the condition.

A brief history of PKU research illustrates how, through commitment to a cause and an unwillingness to accept defeat, we can all make a difference in the detection and prevention of mental handicap.

1933 ■ PKU was discovered by Norwegian physician Ashborn Folling. The discovery was prompted by a mother who noticed a distinctive odour to her child's urine.

■ Dr. Folling developed the first diagnostic test for PKU using Ferric Chloride (when added to the urine of a patient with PKU, the substance turns a bright green colour).

1939 ■ Dr. Richard Block proposed that a special diet might be developed to control phenylalanine levels.

1940s ■ Dr. Joe Wortis requested a grant for research an development of a PKU diet. The application was denied.

- Dr. Horst Bickel, using the Ferric Chloride test at Birmingham Children's Hospital, England, encountered a parent who refused to accept the idea that nothing could be done for her child.
- Using Dr. Block's earlier work as a guide, Dr. Bickel developed and tested the first PKU diet.

1953
- Dr. Bickel presented his findings to mixed response at a pediatrics meeting in Switzerland.
- It was soon suspected that a genetic origin might exist, since those with PKU often had siblings with the same condition.
- Enzyme studies were undertaken, which began to unravel some of the mysteries of PKU.
- Dr. Bickel's diet was adopted widely to control the behaviour of children with PKU.

1950s
- It was discovered that the Ferric Chloride test was effective only in detection of phenylalanine levels that had built up over time. In order to prevent handicap, PKU must be identified before the infant is 30 days old.
- Dr. Robert Guthrie, whose own niece was diagnosed too late for the diet to prevent mental handicap, developed a bacterial inhibition test. Dr. Guthrie devised a procedure for testing blood samples that allowed for early identification. The diet could then be prescribed to prevent brain damage within the critical period.

1961
- The technology for effective screening of PKU, and the new PKU diet were now available...but screening was not being practiced widely.

Since that time, testing for PKU has been made mandatory throughout Canada. The following 1982 statistics record the instances of PKU in six provinces:

British Columbia:
One in every 8,600 births
(Health Surveillance Registry of British Columbia)

Manitoba:
One in every 17,000 births
(Manitoba Department of Health)

Nova Scotia:
One in every 20,000 births
(Nova Scotia Department of Health)

Ontario:
One in every 21,000 births
(Ontario Ministry of Health)

Quebec:
One in every 24,444 births
(Réseau de médécine génétique du Québec)

Saskatchewan:
One in every 18,000 births
(Saskatchewan Department of Health)

The history of PKU demonstrates how a major medical and social problem can be dealt with effectively when there is active involvement from all sources.

Today, PKU can be detected very early and screening is a universal procedure. There is still no single cure, but due to a number of key factors in the development of effective treatment, PKU can now be controlled in most cases.

If the history of PKU can be seen as a success story, it is due to the encouragement and effort by physicians, parents, community and national organizations, public education and commitment by political leaders. The story is not over yet.

Together we can make a difference.

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MAKING A DIFFERENCE:

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Did you know that in this decade, between 200,000 to 600,000 Canadians will either be diagnosed as having a mental handicap or will need services because of a mental handicap?

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- ☐ preventing conditions, circumstances and practices that cause people with mental handicaps to acquire further handicaps and become even more dependent.

By promoting lives of quality, we mean:

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Downsview, Ontario, Canada M3J 1P3
(416) 661-9611